

# The Future of Care for Children with Medical Complexity

**Cafe #5: Health Equity And Anti-  
Ableism Through Family Partnership**

**October 30, 2024**

**Discussants:**

**Nikki Montgomery, MA, MEd, GPAC**

**Michelle White, MD, MPH**



**School of Social Work**

Center for Innovation in Social Work & Health



**This virtual café series is generously funded by**



**Lucile Packard**  
**Foundation**

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Children's Health



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# About the Future of Care for CMC

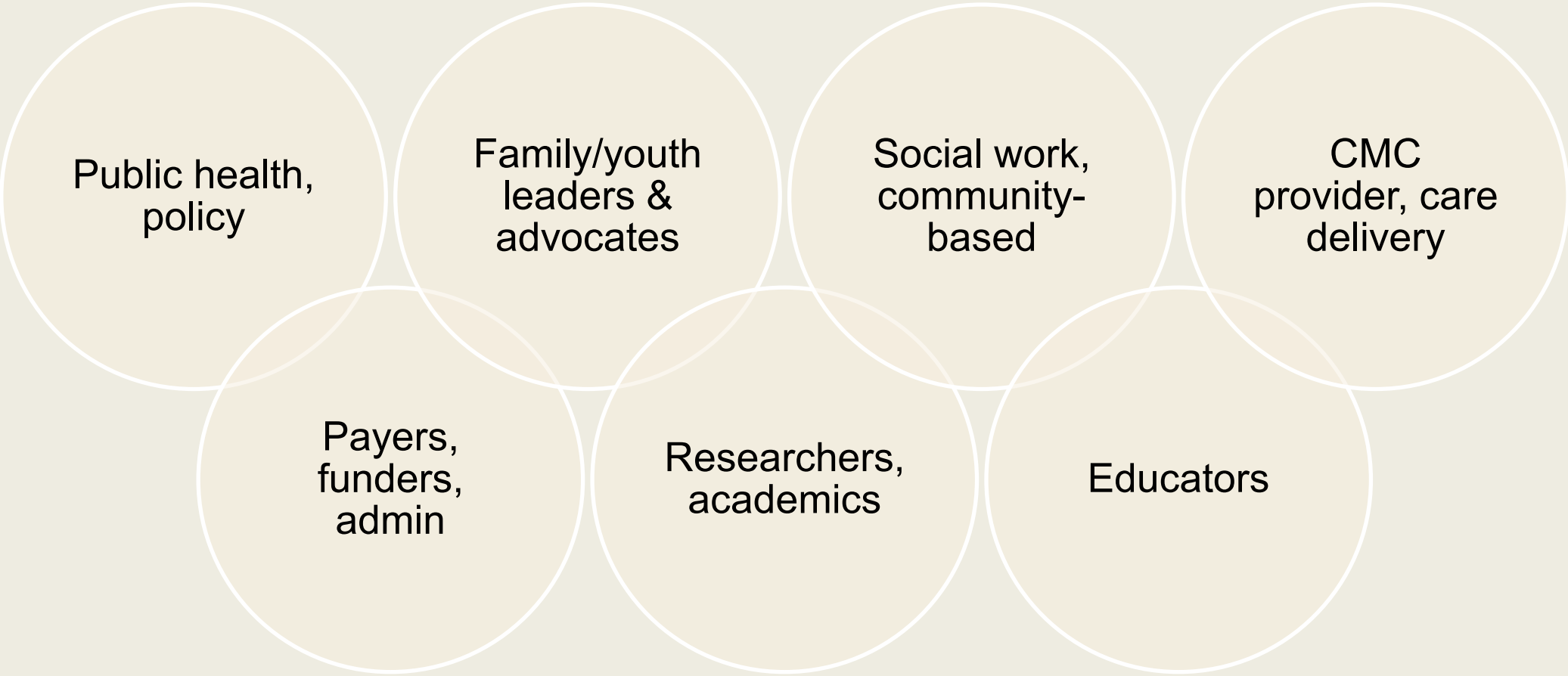
## Virtual Cafe Series

- Aim: To foster interdisciplinary dialogue among participants interested in meaningful systems improvements for CMC
- 60 min sessions: 20 min intro/presentation/Q&A + 25 min facilitated breakout discussion + 10 min share out
- Family partners co-lead every session
- Discussion questions and analysis created by an interdisciplinary faculty





# Who We Are





# Discussion Format

To participate in the discussion,  
please **RAISE YOUR HAND** via Zoom  
or  
**WRITE IN THE CHAT BOX**

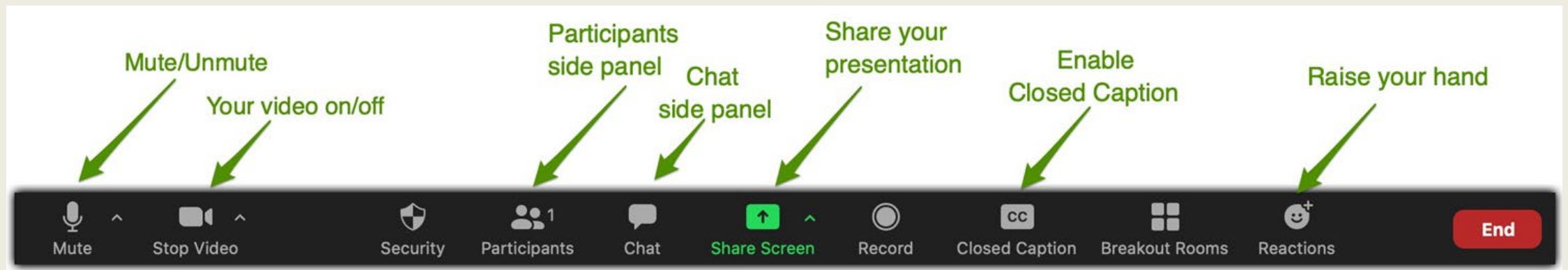
Both are equally valuable ways to participate!

This meeting is being recorded and the  
chat transcript will be saved & analyzed  
with support from AI



# Zoom Platform

## Please Use Your Camera & Mute Your Line





# the FUTURE of CARE

NO CHILDREN with MEDICAL COMPLEXITY

CAFÉ 4

# FAMILY-DRIVEN APPROACH to UNDERSTAND FAMILY WELL-BEING & ITS FACILITATORS

KATIE HUTH



CARING for the CHILD MEANS CARING ABOUT the FAMILY, & PARTNERING with FAMILIES as COLLEAGUES.

ASKING the RIGHT QUESTIONS

THERE IS NOT ONE RIGHT ANSWER

WITH FAMILIES

BREADTH and DEPTH

EVERY VOICE COUNTS

JAY BERRY



How CAN WE ACTUALLY IMPLEMENT our FINDINGS?

BEYOND ACADEMIC PUBLICATIONS

## KEY IDEAS from BREAKOUTS:

THIS WORK IS DYNAMIC

MEANINGFUL WAYS of ASSESSING FAMILY WELL-BEING?

AND these ISSUES are LONG-STANDING



IMPROVING POLICY

IDENTIFY INADEQUACIES



MEDICAL PROFESSIONALS' PREP & COMMUNICATION



WHAT IS FEELING HARD for YOUR FAMILY RIGHT NOW?

COMMUNICATION SKILLS

TRAINING on ASSESSMENT



WHAT IS NOT BEING SAID

PROMOTE DIVERSITY in PROFESSIONAL EDUCATION

WAYS to EDUCATE/ BUILD AWARENESS?

GETTING INFO TO FAMILIES where they ALREADY ARE



IMPROVING PROFESSIONAL EDUCATION through Stories

FOLLOW-UP AFTER ASSESSMENT

SUPPORT SYSTEM

MAKING INFO ACCESSIBLE

FAMILY TRACKS at CONFERENCES!



NIKKI MONTGOMERY



FAMILY WELL-BEING

PARENT of a MEDICALLY COMPLEX 13-YEAR-OLD!

COMPLEXITY — RICH, AUTHENTIC FAMILY ENGAGEMENT PROCESS

NOT JUST GETTING CARE... IT'S ABOUT QUALITY CARE

300 FAMILIES  
800+ IDEAS!

LISTEN! COORDINATE CARE RECOGNIZE FAMILY EXPERTISE MAKE TRANSITIONS EASY

FINDING PRACTICAL SOLUTIONS WITH PEOPLE EXPERIENCING the PROBLEM.



FOLWS ON WHOLE FAMILY WELL-BEING



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Illustrated by KARINA BRANSON CONVERSKETCH.COM



# Guidelines to Support Respectful Dialogue

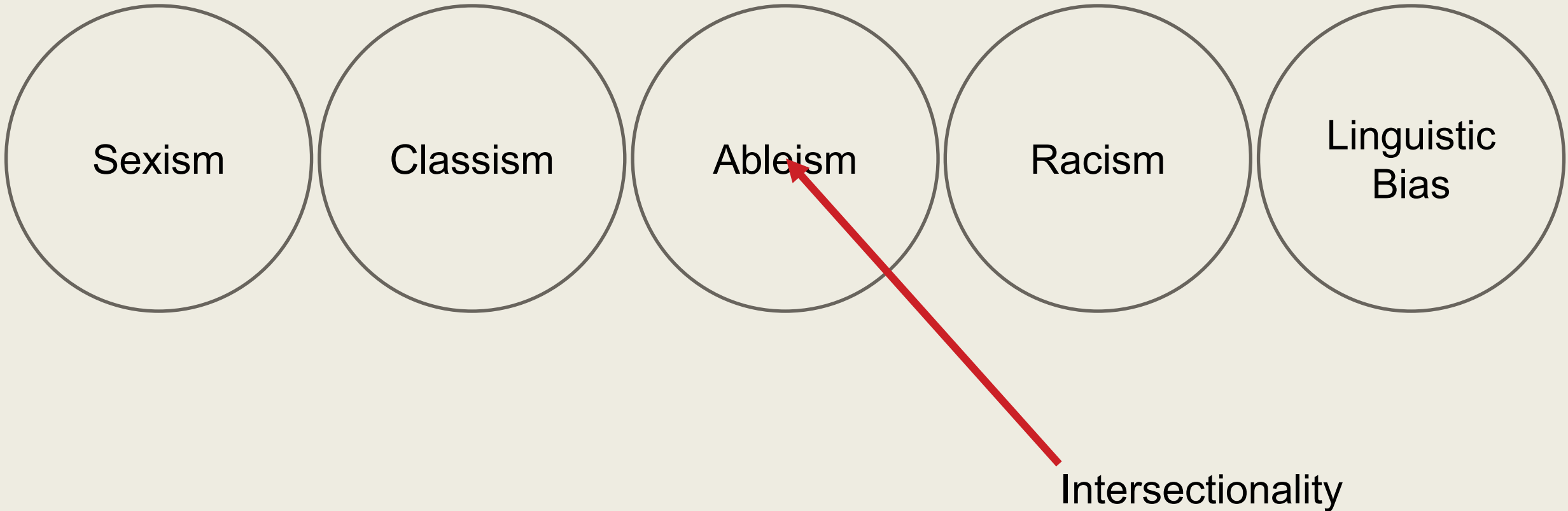
- CMC CoIN theme: Families of CMC experience pervasive bias
  - Underpinning of each café & discussion materials
  - Family partnership as essential
- Sensitive and sometimes emotionally charged topic!
- Focus on listening with curiosity and care
- Assume best intentions
- Take advantage of our time together to consider how we can individually and collectively address bias and potential harm across disciplines and perspectives in tangible ways







# About Ableism and Intersectionality





# Responses to Bias in Healthcare

- Stereotype threat
- Lack of trust or diminished trust
- Avoidance of the care setting



# Beyond Building Character

- Recognizing and addressing bias is **not about building character**.
- “Virtue signaling” about not having biases is false and can do much more harm than good.
- Bias is a matter of **life and death**, especially for people who have intersectional identities, including children with medical complexity.



# Mitigating Bias through Partnership with Families

- Engaging families as leaders in the care of their children at the individual level supports stronger relationships. (humanize)
- Engaging families in community-level and advisory work ensures that diverse perspectives guide initiatives and that differences are considered and accounted for. (listen)
- Engaging families in systems-level change can ensure that diverse perspectives and needs are included in policy and practice changes. (co-create)



# Confronting Bias (Individual Level)

- We all have bias!
- Suggestions for addressing bias
  - Be curious!
  - Who do I feel most comfortable around? Why?
  - Who do I feel less comfortable around? Why?
  - Surround yourself with people with different life experiences than you
  - When you experience a strong emotion or intuition, take time to ask yourself why (even better talk it over with someone who you can trust)
  - Be humble!





# Confronting Bias (Systems Level)

- Be curious and ask questions
- Family and patient engagement: Who is not at the table but should be?
- Are all children benefiting equally from a program or innovation? How can I assess the equity of this program?
- Engage someone with experience in health equity, be aware of identity taxation
- Address a big problem with small steps
- Partner with other disciplines





# Harm from Bias: Child Welfare

The hospital is full so you are encouraged to discharge patients as soon as possible. While reviewing your patients before rounds you read about a patient transferred out of the ICU overnight to your team. The patient, a 7yo F, has a history of asthma and has been admitted multiple times over the prior 2 years. Later on during rounds you examine her and find that she is now ready for discharge. After you leave the patient's room, a member of the care team walks up to you to suggest that you make a report to CPS because the patient is not attending her pulmonary appointments.





# Harm from Bias: Child Welfare

Later, you call the patients mother and learn she lives about 1 hour from the pulmonary clinic. She has multiple children and works full time. She tries to attend appointments with her child but if she misses one the next opening is usually 3-4 months away.





# Harm from Bias: Child Welfare

- Black parents are caregivers disproportionately represented in child welfare systems due to interpersonal and structural racism
- Parents with lower SES are more likely to be involved in the child welfare system due to bias, food and housing insecurity



# Recommended Resources

- Danielson B. Confronting Racism In Pediatric Care. *Health Aff (Millwood)*. 2022 Nov;41(11):1681-1685. doi: 10.1377/hlthaff.2022.01157. PMID: 36343317.
- Victoria Parente, Michelle J. White; Equity Is Multilingual: A Call for Language Justice in Pediatric Hospital Medicine. *Hosp Pediatr* February 2023; 13 (3): e51–e53. <https://doi.org/10.1542/hpeds.2022-007077>
- Brown CE, Marshall AR, Snyder CR, et al. Perspectives About Racism and Patient-Clinician Communication Among Black Adults With Serious Illness. *JAMA Netw Open*. 2023;6(7):e2321746- e2321746. doi:10.1001/JAMANETWORKOPEN.2023.21746
- Slopen N, Chang AR, Johnson TJ, et al. Racial and ethnic inequities in the quality of paediatric care in the USA: a review of quantitative evidence. *Lancet Child Adolesc Health*. 2024;8(2):147-158. doi:10.1016/S2352-4642(23)00251-1







Questions?  
Comments?



# Facilitated Breakout Discussion – Grab your coffee!

- Aim: To consider together actionable strategies, resources, and leverage points for change
- CMC Parent “Our Whole Life is a Quality Improvement Project”
- Collective **wisdom** and collective **impact**:  
It’s going to take ALL of us; we ALL matter
- Keep larger aspirational vision in mind AND make changes where we can now
- Multiple modes to capture breadth of perspectives – spoken AND chat
- ConverSketch: Karina Branson will bring the discussions alive visually afterwards



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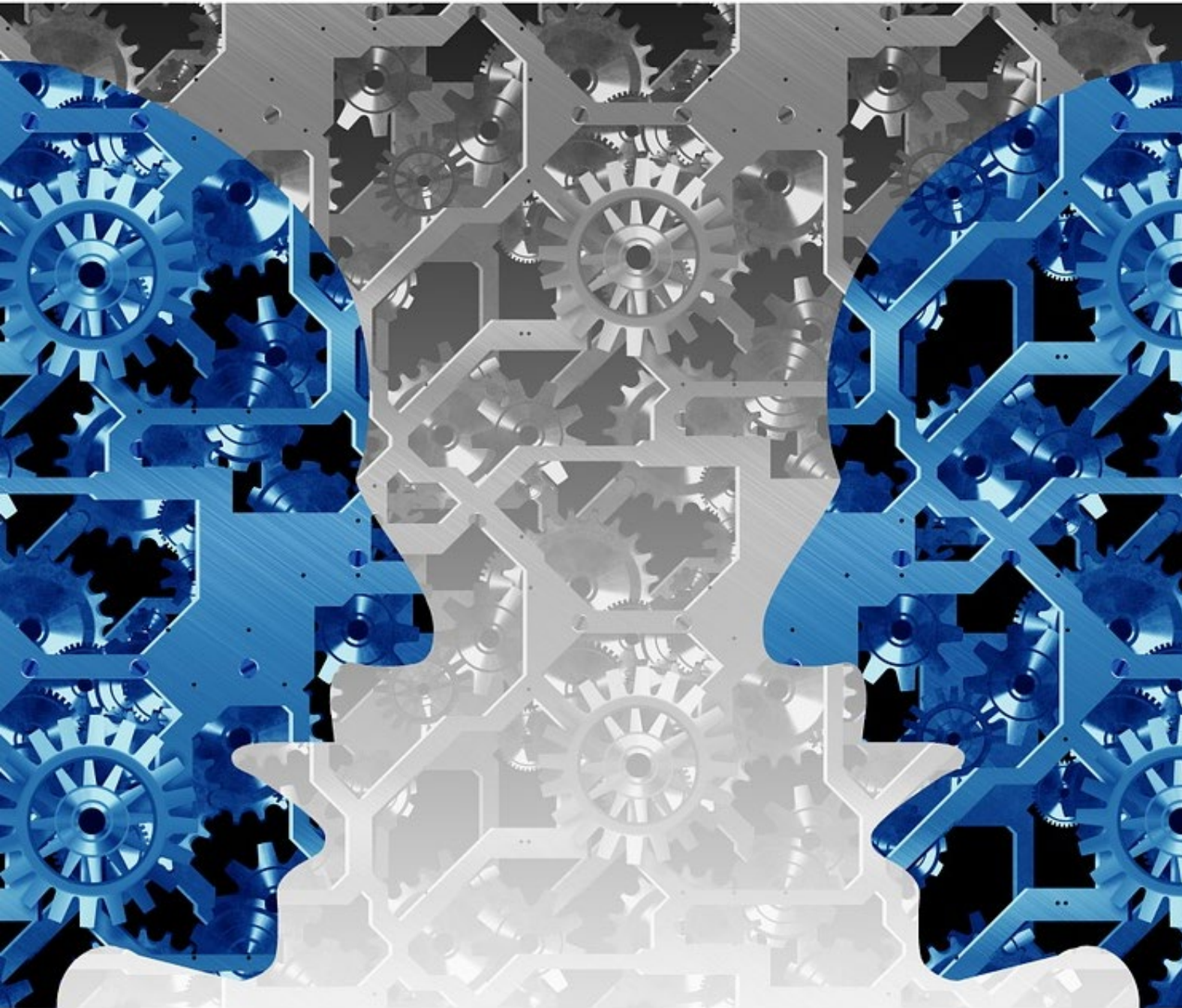
# Going into Breakouts

- Randomly pre-assigned
- 4 breakouts w/ 2 co-facilitators each (one family partner)
- 25 minutes for discussion
- Automatically close
- Family Partner Facilitators share out one highlight
- Participants chat key takeaways

\*\*breakouts will be recorded to be synthesized, packaged, and shared out (supported by AI)\*\*







# Group Share Out

- Family Partner Facilitators share one highlight out loud
- Participants share one takeaway in the chat

# **THE FUTURE OF CARE FOR CMC VIRTUAL CAFÉ #6: SUSTAINABILITY AND STRATEGIC PARTNERSHIPS**



Photo courtesy of Jaren Wicklund/Bigstock.com

**Wednesday, December 4, 2024**

**4:00 – 5:00 PM ET**

**Zoom**

**Co-  
Discussants:**

**Jeff Schiff, MD,  
MBA**

**Rich Antonelli,  
MD, MS**

**lead facilitation  
by Meg  
Comeau, MHA**





# Evaluation Survey

Link in the chat box:

[https://bostonu.qualtrics.com/jfe/form/SV\\_8qVU3saqaoOjeho](https://bostonu.qualtrics.com/jfe/form/SV_8qVU3saqaoOjeho)

*Any additional thoughts will be included in our thematic synthesis for this session*



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# Contact Us!

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